



## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### Health Resources and Services Administration

#### Agency Information Collection Activities: Proposed Collection: Public Comment Request;

#### Information Collection Request Title: Be The Match® Patient Support Center Survey

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services.

**ACTION:** Notice.

**SUMMARY:** In compliance with the requirement for opportunity for public comment on proposed data collection projects of the Paperwork Reduction Act of 1995, HRSA announces plans to submit an Information Collection Request (ICR), described below, to the Office of Management and Budget (OMB). Prior to submitting the ICR to OMB, HRSA seeks comments from the public regarding the burden estimate, below, or any other aspect of the ICR.

**DATES:** Comments on this ICR should be received no later than **[INSERT DATE 60 DAYS AFTER DATE OF PUBLICATION IN THE *FEDERAL REGISTER*]**.

**ADDRESSES:** Submit your comments to [paperwork@hrsa.gov](mailto:paperwork@hrsa.gov) or by mail at: HRSA Information Collection Clearance Officer, Room 14N39, 5600 Fishers Lane, Rockville, MD 20857.

**FOR FURTHER INFORMATION CONTACT:** To request more information on the proposed project or to obtain a copy of the data collection plans and draft instruments, email [paperwork@hrsa.gov](mailto:paperwork@hrsa.gov) or call Samantha Miller, the HRSA Information Collection Clearance Officer, at (301) 443-1984.

**SUPPLEMENTARY INFORMATION:** When submitting comments or requesting information, please include the ICR title for reference.

*Information Collection Request Title: Be The Match® Patient Support Center Survey,*

*Abstract:* The C.W. Bill Young Cell Transplantation Program was established by the Stem Cell Therapeutic and Research Act of 2005 (Public Law [Pub. L.] 109-129) and was reauthorized in 2010 (Pub. L. 111-264), 2015 (Pub. L. 114-104) and again in 2021 (Pub. L. 117-15). The C.W. Bill Young Cell Transplantation Program's Office of Patient Advocacy (OPA) is operated by the National Marrow Donor Program® (NMDP). Through OPA, NMDP provides navigation services, education resources and support to people in need of or who have received an allogeneic hematopoietic cell transplant (HCT). As the contractor for the OPA, NMDP is required to conduct surveys to evaluate patient satisfaction with the services provided. As such, NMDP will elicit feedback from HCT patients, caregivers, and family members who had contact with the NMDP/Be The Match® Patient Support Center (PSC) for service and support. The survey is administered through a web-based system. In addition to questions that measure satisfaction, the survey also includes demographic questions to determine representativeness of findings.

*Need and Proposed Use of the Information:* HCT is a complex medical procedure that requires significant support before, during and after the procedure. Many patients experience barriers that impede access to HCT. Barriers to HCT-related care and educational information are multi-factorial. The NMDP/Be The Match PSC offers many programs and services to support patients, caregivers, and family members throughout their HCT journey. Feedback from recipients of NMDP services is essential to understand the changing needs for services and information as well as to demonstrate the effectiveness of existing services. The primary use for information gathered through the survey is to determine the helpfulness of participants' initial contact with the PSC patient navigators and to identify areas for improvement in the delivery of services. Patient navigators are trained lay or licensed clinical patient navigators, who respond to requests for information and support. Program managers and NMDP leadership use this evaluation data to share patients' experiences as well as make program and resource allocation decisions.

Web-based surveys will be administered to all participants (patients, caregivers, and family members) who have contact with the PSC. All participants for whom an email address is known will be invited to complete the survey online. Survey respondents will be notified via email invitation and in the survey instructions that participation is voluntary, and responses will be kept confidential. A follow-up invitation will be sent within 2 weeks to non-respondents.

The survey will include these items to measure: (1) their experience, (2) if the contact helped the participant feel more confident in coping with treatment, (3) if the contact helped the participant feel more hopeful, (4) if the contact helped the participant feel less alone, (5) increased awareness of available resources, (6) if the contact helped the participant feel more informed about treatment options, (7) if their questions were answered, and (8) types of challenges faced by participant. The survey data will be analyzed quarterly and annually, and results will be shared with program managers. Feedback indicating a need for improvement will be reviewed by program managers biannually and implementation of resulting program changes or additions will be documented.

*Likely Respondents:* Respondents will include patients, caregivers, and family members who have contact with the PSC via phone or email for HCT navigation services and support (advocacy). The decision to survey all participants was made based on the historically low response rate to this survey due to patients' frequent transitions in health status as well as transfer between home and the hospital for initial treatment and care for complications. Participants will receive the survey once in a 1-year cycle. If a participant contacts the PSC one or more years after the initial contact, they will receive a second survey. This is because we anticipate that the participants' needs will likely change during the time lapse.

*Burden Statement:* Burden in this context means the time expended by persons to generate, maintain, retain, disclose, or provide the information requested. This includes the time needed to review instructions; to develop, acquire, install, and utilize technology and systems for the purpose of collecting, validating, and verifying information, processing and maintaining

information, and disclosing and providing information; to train personnel and to be able to respond to a collection of information; to search data sources; to complete and review the collection of information; and to transmit or otherwise disclose the information. The total annual burden hours estimated for this ICR are summarized in the table below.

The total respondent burden for the customer satisfaction surveys is estimated to be 153 hours. HRSA expects a total of 900 respondents to complete the Be The Match® Patient Support Center Survey.

Total Estimated Annualized Burden Hours:

Form Name	Number of Respondents	Number of Responses per Respondent	Total Responses	Average Burden per Response (in hours)	Total Burden Hours
Be The Match® Patient Support Center Survey	900	1	900	0.17	153
Total	900	1	900	0.17	153

HRSA specifically requests comments on (1) the necessity and utility of the proposed information collection for the proper performance of the agency's functions; (2) the accuracy of the estimated burden; (3) ways to enhance the quality, utility, and clarity of the information to be collected; and (4) the use of automated collection techniques or other forms of information technology to minimize the information collection burden.

**Maria G. Button,**

*Director, Executive Secretariat.*

